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ABSTRACT

This "Feature Issue" of the quarterly journal "Impact" presents 19 brief articles on family support systems in the United States for persons with developmental disabilities and their families. Emphasis is on provisions of Public Law 99-457. Articles include: "Family Support in the United States: Setting a Course for the 1990s" (James Knoll); "Keeping Families Together: Subsidies, Waivers, and CHCO (Children's Home Care Option)" (Thomas R. Fields); "Rx: Children's Home Care Option:" (Georgianna Larson); "Federal Law Gives Families Control of Services to Their Young Children" (Norena Hale); "Legal Empowerment" (Stephen E. Scott); "Integrating Parents with Agency Staff" (Matthew M. Pope); "Kyle's Success Story" (Linda Horkheimer); "Training Families to be Case Managers" (Marijo McBride); "Technology as Family Support" (Rachel Wobschall and Erik Aasland); "Computers: Accessing a New World of Opportunity" (Jon Skaalen); "From Surviving to Thriving: One Family's Transformation" (Cindy Scattergood); "Teen Sitters Offer Child Care Alternative" (Anita Lavasseur); "Residentiality: Giving Families a Break" (Maureen Horton); "In-Home Support from a User's Point of View" (Dorothy and Edward Skarnulis); "ARC (Association for Retarded Citizens)=Parent Power" (Karen Grykiewicz); "Project Seeks Answers from Families" (Ann and Rud Turnbull); "Families Educating Policymakers About Family Support" (Fran Smith); "Minnesota's Partners in Policymaking" (David Hancox and Thomas Zirpoli); "Personal Futures Planning: A Focus on the Positive" (Kay Zwernik).

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Feature Issue on Family Support

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Family Support in the United States: Setting a Course for the 1990s

by James Knoll

During the decade of the 1980s, the family agenda finally made it onto center stage in state and national policy deliberations. As the decade progressed, terms such as "day care," "parental leave," and the "mommy track" appeared with increasing frequency in the daily news. As family concerns in general gained prominence, there were increasing calls for policymakers and providers to stop "supplanting" families of people with disabilities and start supporting them. These pressures, coupled with changes in the political and economic climate, ushered in a period of unparalleled interest in the development of services for people with disabilities within the family home.



While the last 10 years have seen growing interest in family support, attempts to track these developments underscore the often tentative and embryonic nature of these efforts in the U.S. Examination of state efforts done just a few years ago are completely out of date. Each new fiscal year brings substantial change to the depth and breadth of family support programs. Though much of the change is positive and reflects expansion, many programs no longer exist because they were pilot projects that did not become permanent. Further, many family support initiatives are not firmly established by legislative mandate and therefore, while they may continue, are susceptible to the vicissitudes of the state budgetary process. In response to this lack of current knowledge, Human Services Research Institute has, with funding from the Administration on Developmental Disabilities, completed a series of interviews with informants in every state and has developed an end-of-the-decade status report on family supports.*

The end-of-the-decade report reveals that as of December 1, 1989, 41 states had programs that focused on supporting families raising a child who has a developmental disability. These programs provided some service to

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From the Editors:

Family support is a term that is defined and utilized by each family in their own individualized way as they strive to reach beyond survival to the vision of life they wish to realize for their family and for their members with disabilities. For LuAnn Jelinek (pictured here with her daughters Katie and Becky, and her husband Doug), family support has, among other things, included the training she's received through the Parent Case Management Project (see page 7). That project, in her words, "...assumes competency in families and supports us in furthering ourselves..." This issue of IMPACT shares personal stories about families like the Jelineks who are finding the support and empowerment they need from a variety of sources. It also highlights national, state, and local programs that are addressing the issues of family support. It is our hope that this collection of articles will reveal both the challenges and possibilities of family support, offering encouragement to those seeking to meet the needs of their own or others' families.

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A report from the Research and Training Center on Community Living and the Institute on Community Integration at the University of Minnesota. Dedicated to improving community services and social support for persons with developmental disabilities and their families.

Keeping Families Together: Subsidies, Waivers, and CHCO

by Thomas R. Fields

Prior to 1975, Minnesota families with children with developmental disabilities had two difficult choices: placing their child in an institution to get the services they needed, or trying to make a life for their child at home with little or no outside assistance available. But that year, a group of parents and advocates who refused to accept these choices were able to convince the state legislature that providing a small amount of assistance to families was often all that was required to keep a child with his or her family, and out of placement. The legislature funded a pilot program that assisted 50 families with cash payments of up to \$250 per month. Evaluation proved the program to be successful, and legislation was passed making the Family Subsidy Program permanent.

In 1981, Congress passed legislation which allowed states even more latitude in assisting families to keep their children with developmental disabilities at home. The legislation allowed states the option of applying for a waiver of certain Medicaid statutory requirements to allow the provision of home and community-based services for persons who would otherwise require placement in facilities funded by Medicaid. For the first time, Medicaid dollars were available to serve persons living in community settings, including children living with their families. Minnesota applied for a waiver in 1984, and in July of that year the Home and Community-Based Waivered Services program became another resource for families.

In 1988, the Minnesota legislature approved the state's participation in the TEFRA option. This option allows the state to waive the deeming of parental income and assets in determining eligibility for the Medical Assistance program for certain children with disabilities who are at risk of placement in an institution or hospital. The Children's Home Care Option (CHCO), as it's known in Minnesota, now allows moderate and middle income families to access services through the Medical Assistance program for their children with mental retardation, autism, mental illness, physical disabilities, medical fragility and other conditions requiring institutional care.

Today, the Family Subsidy program, the Home and Community-Based Waiver program, and the Children's Home Care Option enable over 1,100 Minnesota children with developmental disabilities to receive the care they need while living at home with their families.

■ The Family Subsidy Program

Minnesota families with a biological or adopted son or daughter who is under age 22, has mental retardation or a related condition, and is either in, or at risk of, placement outside the family home, are eligible for a grant through the Family Subsidy Program. The program provides cash grants to enable the families to purchase services and items necessary for the son's or daughter's care. Eligibility is not tied to family income; rather it is related to the family's need for a grant to maintain its family member with a disability in the family home.

Families are paid by check monthly, in amounts up to \$250 (in certain emergency situations, the amount can exceed the \$250 limit.) Grants are used to purchase items and services that are a part of the child's approved Individual Service Plan (ISP), the plan required by Rule 185 for all persons receiving publicly-

funded developmental disabilities services in the state. Family Subsidy funds may only be used to purchase items and services that are not funded by other public programs for which the family is eligible. For example, the grant cannot be used to pay for anything reimbursable through Medical Assistance, if the family is eligible for that program. Some of the more common items and services families purchase with their grants are: respite care, both in home and out-of-home; special clothing; special dietary needs; specialized equipment such as wheelchairs and therapy equipment; medical costs and medications for which Medical Assistance or insurance reimbursement is not available; modifications to the home and vehicle to ensure accessibility; other environmental adaptations, such as adaptive switches; family therapy, or individual therapy for parents or siblings; and higher daycare expenses due to the child's disability. Other items and services that are directly related to the disability, are beyond normal child rearing expenses, and are necessary for the care of the child, can also be purchased with program funds.

Application for Family Subsidy is made by the family with the assistance of the case manager, and is submitted by the county agency to the Minnesota Department of Human Services (DHS). DHS evaluates each application and assigns it a rating, based on severity of need. Criteria used to determine need for a grant include: potential for placement outside the home, severity of the child's disability,

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amount of family stress resulting from child's disability, and other factors, such as family size, resources available to the primary caregiver, and presence of disabilities in other family members. The rating establishes each eligible applicant's place on a waiting list. The waiting list is not first-come first-served; an applicant's status continually changes as new applications are received and grants are awarded to eligible applicants. Grants are awarded as openings occur.

Currently, the legislature has appropriated \$1,128,700 for the program, which allows approximately 410 families to be served. Next fiscal year, which starts July 1, 1990, grants for an additional 25 families will be added.

Families served are generally moderate to middle income. Most of the children with disabilities have severe or profound mental retardation, multiple handicaps, and/or are labeled "medically fragile". Over 90% of the participating families are eligible for Medical Assistance, largely through the Children's Home Care Option.

■ The Home and Community-Based Waivered Services Program for Persons with Developmental Disabilities

A unique feature of the Home and Community-Based Waivered Services program is the flexibility it offers in the

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Rx: Children's Home Care Option

by Georgianna Larson

The Children's Home Care Option (also known as the TEFRA Option) has been highly successful, with over 1000 Minnesota children enrolled in 18 months. But program success cannot be measured by enrollment—the real measure of success is consumer satisfaction, as illustrated in the stories of these three Minnesota families.

The Murrays: Beth Murray is 10 years old. Regular Medical Assistance gave Beth only four hours a week of personal care assistance and her mom, Anne, spent most of her days with Beth's personal care tasks such as feeding and bathing. In 1988, the Children's Home Care Option opened up a new world for Beth and her family. The increased personal care hours (up to 60 hours a week at home and school) allow Anne to "be a more effective mom to both of my kids. It allowed me to relearn to be a mom, rather than a care provider, to Beth and gives me more time to spend with my other child, John." Anne's advice to other families is, "We have an obligation to provide health care for our children. If that involves using a different type of coverage than we were brought up to believe in or value, then I think we need to swallow our pride and provide that care."

The Follmers: "TEFRA takes away the family's biggest stress — how to pay the medical bills", says Jackie Follmer. She is the mother of Charlie who is 18 months old and ventilator-dependent. Most of the coverage for Charlie's needs, including 24 hour a day home nursing, is provided by the family's HMO. The Children's Home Care Option (TEFRA) supplements that care by paying for medications and personal care items. Jackie doesn't think that they could afford to have Charlie home without the extra help that TEFRA provides. "There's no way a family can pay for home care like this alone. We tried to get SSI for Charlie, but we were denied due to our income. He can get SSI in the hospital, but there weren't any extra bills then. The extra bills came after he came home."

The Bittners: Nineteen month old Andy Bittner will have his services on the Children's Home Care Option cut dramatically this month—and his family couldn't be happier! He has been home for 13 months on a ventilator with 24 hour nursing. His physical condition has improved to the point that he no longer needs the ventilator or the home nursing services. His road to good health has been long and expensive. The Bittners exhausted lifetime maximums of two insurance policies for Andy in one year. The Children's Home Care Option was approved one month after their insurance policy lapsed, and allowed the family to keep Andy home. "That has been the best benefit of the program", says Joy Bittner, Andy's mom. "The nurses in the hospital can love him, but they can't replace mom and dad."

Three families with different experiences and services available through the Children's Home Care Option. The common threads are the ability for their children to be at home with their families, for the parents to be able to spend time with parenting tasks, and relief from the stress of unpaid medical bills. Cost effective, family-centered care: isn't that the best end to this story?

Georgianna Larson is Executive Director of Pathfinder, a project to improve systems of care for children with chronic health conditions, located at 5000 W. 39th Street, Minneapolis, MN 55416. In the fall of 1990, Pathfinder will publish a parent handbook on financing programs for Minnesota families with children who have special health needs.

Federal Law Gives Families Control Of Services to Their Young Children

One of the minimum components of a statewide comprehensive early intervention system under Part II, P.L. 99-457, The Early Intervention Program for Infants and Toddlers with Handicaps, is the Individual Family Services Plan (IFSP). The IFSP represents a shift from child-centered planning done by a single agency toward coordinated interagency multidisciplinary planning enhancing the capacity of each family to meet the unique needs of their child from birth through age three. Quoting from the Comment section of P.L. 99-457, "It is important that the degree to which the needs of the family are addressed in the IFSP process is determined in a collaborative manner with the full agreement and participation of the parents of the child. Parents retain the ultimate decision in determining whether they, their child, or other family members will accept or decline services under this part." More specifically, the federal laws and rules state that the IFSP be jointly developed by the family and appropriate qualified personnel; be based on the multidisciplinary evaluation and assessment of the child and the assessment of the child's family (voluntary); and include services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child.

The Rules specify that the following must be included in each IFSP:

- A statement of the child's present levels of physical development, cognitive development, language and speech development, psychosocial development, and self-help skills which is based on professionally acceptable objective criteria.
- With the concurrence of the family, a statement of the family's strengths and needs related to enhancing the development of the child.
- A statement of major outcomes expected to be achieved for the child and family; the criteria, procedures, and timelines used to determine the degree to which progress is being made; and whether modification or revisions are necessary.
- A statement of the specific early intervention services necessary to meet the unique needs of the child and the family to achieve the outcomes, including the frequency, intensity, location, and method of delivering the services, and the payment arrangements, if any.
- Other services and the steps that will be undertaken to secure those services.
- The projected dates for initiation of the services and anticipated duration.
- The name of the case manager who will be responsible for implementing the IFSP and coordinating the agencies.

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One Parent's View of P.L. 99-457

The following comments come from Jeanette Bahr's testimony on P.L. 99-457, delivered in a national hearing before the Governmental Relations Committee, Division of Early Childhood, of the Council for Exceptional Children. Ms. Bahr is a member of Minnesota's Interagency Coordinating Council on Early Childhood Intervention.

If people ask me how I am these days, I answer, "Still kicking!" I don't mean that in a negative sense, but with three children, ages 18 months, 3 and 7, to say "fine" seems quite misleading. My oldest daughter Katy is beautiful, active, and challenging. Katy was diagnosed with autism at about one year old. Our experience with early intervention precedes P.L. 99-457 and I must say much of my perspective comes from looking back and wishing this mandate had passed earlier. I am convinced that this policy is based on values that I share: strengthening families, building formal and informal supports for families, and enhancing communication.

As this excellent law is carried out, however, it is crucial that the implementation - a means employed to achieve a given end - does not supersede the intent which is to enhance the development of infants and

toddlers with disabilities and to enhance the capacities of families. While measures, interagency agreements, and so on are important, they still must be viewed as a vehicle to accomplish the broader goal of strengthening families. It is my concern that some of the language in the federal regulations undermines this goal.

In Section 300.322 (Evaluation and Assessment), family strengths are assessed. This word strengths sets up a value judgment artificially imposed on a family. A family rated as "strong" may in fact fall apart because it is subsequently not given support. Even worse, a family rated as "weak" may be prevented from growing and coping by the perceptions of professionals. A poor rating may follow a family for years and, most likely, become self-fulfilling.... This judging of family strengths

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Legal Empowerment

by Stephen E. Scott

Legal Advocacy for Persons with Developmental Disabilities is a state-wide project of the Legal Aid Society of Minneapolis that addresses the special legal needs of persons with disabilities. Based on its long history of high quality representation of low income people, the Legal Aid Society has been designated as the official agency to protect and advocate for the rights of Minnesotans with developmental disabilities. The mission of Legal Advocacy is to ensure that persons with developmental disabilities are protected from abuse and discrimination, and receive the services they need in order to live as independently and productively as possible. Legal Advocacy uses several strategies to further this mission, including representing people with disabilities in enforcing their rights (case advocacy) and educating persons with disabilities and their families.

Case Advocacy

People usually contact Legal Advocacy because they do not know what services they can get or how to get them, or because they have exhausted the informal channels available and still are not receiving those services they need and believe they are entitled to. After a careful analysis of the issues and pertinent law, staff help families understand the legal options available to them. This legal advice often provides the necessary information so that people can resolve issues themselves informally. In other situations, however, Legal Advocacy must assist in negotiations, hearings, or court proceedings.

Legal Advocacy's litigation efforts have led to major improvements in services to children and adults with developmental disabilities. Legal Advocacy's litigation in a federal class action, initially titled *Welsch v. Likins*, led to improvements in conditions in state institutions and the movement of

hundreds of residents into the community. In another Legal Advocacy case, the Supreme Court required counties to provide persons with mental retardation with the day training and habilitation programming their needs required. And, Legal Advocacy's representation of students in due process hearings has served as a major impetus towards integration of children with disabilities with their non-disabled peers in schools.

Public Education

Legal Advocacy conducts over 75 workshops each year for persons with developmental disabilities and their parents, advocates, and professionals. Topics covered have included early childhood services, integration, transition, county case management, residential rights, guardianship, standards for services, and discrimination. A special focus this year will be training on early childhood services in northeastern Minnesota. Legal Advocacy also has available for purchase educational materials, including a workbook on early childhood services and a quarterly law report that is available on a subscription basis.

The primary source of income for Legal Advocacy is federal money that funds states' projects to protect and advocate for the rights of persons with developmental disabilities. It also receives sizeable grants from the McKnight, Ordean and Gamble/Skogmo Foundations and the Northeastern Minnesota Initiative Fund. Because of this funding, Legal Advocacy is able to provide services free of charge, with the exception of reimbursement for litigation related expenses.

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reminds me of the joke about a cross between a pit bull terrier and a collie. First, it bites you, then it runs for help. We must *elicit* the areas of concern from the family rather than imposing value judgments on it. Rather than use the word strengths, it should be *family priorities* or *family concern*.

On a similar note, it is the intent of P.L. 99-457 that parents and professionals collaborate. The voluntary nature of family assessments should be clearer in legislation. It should be a family's right to an outside assessment as in P.L. 94-142. The same mechanism of a hearing procedure to determine if the agency or the independent assessment stands would resolve disputes. If a family is deeply concerned about its child's development after an assessment it should have some recourse.

We have learned from P.L. 94-142 the dangers and limitations of segregated sites. Public Law 99-457 should take language from the regulations (Section 303-12 Early Intervention Services) that to the extent appropriate early intervention services must be provided in types of settings in which infants and toddlers without handicaps would participate....

Finally, it is critical that professionals understand the real intent of P.L. 99-457 is to strengthen families. Not provide a certain level of service, not do a certain assessment, but understand a family's values and philosophy - without judging - and then ask the family how it would like to build support.... To illustrate, I compare parenting any child to a dance; sometimes it is exhilarating and joyful, sometimes exhausting. Adding all the professionals can be most confusing unless we remember that parents pick the music and professionals help us with the steps we don't already know.

Reprinted with permission from "Still kicking, mother seeks to improve the law", in Pacesetter, January 1990, published by PACER Center, Minneapolis.

Integrating Parents with Agency Staff

by Matthew M. Pope

In 1977, the Eastern Los Angeles Regional Center for the Developmentally Disabled initiated their Parent Program Coordination Project. Based on the model of the neighboring Orange County Regional Center PPC program, it was designed to place more responsibility and decision making authority into the hands of parents. Parents who were interested in coordinating their son's and daughter's cases attended initial training that covered service provision, disabilities, law, evaluation, program planning, and other related subjects. Once trained, parents were supervised as interns for six months. They became responsible for conducting an annual developmental evaluation, writing the Individual Program Plan, and providing quarterly progress reports. Parents were given a copy of the case file, providing them access to necessary clinical information on their son or daughter for use during doctor visits, school meetings or similar appointments.

During training, parents often noted that simply by doing the things parents do they were already acting as program coordinators before ever hearing of the concept. The training, however, gave them the expertise to navigate through the complex service system.

During the internship and after, trainers found that some parents could not or would not act totally independently as Parent Program Coordinators. The trainers realized that some support would always be necessary, to greater and lesser degrees, for many. The focus of the project changed from one of advocating for total independence for the Parent Program Coordinators, to emphasizing that parents, no matter at what level they participated in service coordination, should be the primary coordinators. Center staff provided whatever emotional, technical, informational, or advocacy support was needed by each individual parent.

The next step in the promotion of parent-professional interaction in the agency came in 1984 with the hiring of parents as Peer Consultants. Notices for the part-time positions were provided to Parent Program Coordinators, opening for them a type of parent career ladder within the regional center system. They could transition through various levels of involvement with family and community into a paid position.

The primary purpose for development of the Peer

Consultant position was to build on what parent support groups had found: that parents could talk more easily to other parents and that another parent "knows what it's like" to have a child with unique needs. But, in the five years of the Peer Consultant program's operation, unexpected dividends have developed in addition to the provision of consumer friendly service.

Once they began working on the inside, the parents

became valuable resources for the professionals. Between the PPC Project's two professional staff, three Peer Consultants, and 200 Parent Program Coordinators, a vibrant camaraderie has developed. The parent to professional relationships are just as trusting and workable as the parent to parent relationships. While Parent Program Coordinators have certainly benefitted from their interaction with the Peer Consultants, it has been a mix of parents and professionals au-

thentically collaborating with each other that has made the difference in the quality of relationships.

It has also been surprising to see the effect parents have had on staff outside of the Parent Program Coordination Unit. With a counseling staff of over 40 professionals, interaction could have been intimidating for the three Peer Consultants, none with a college degree. However, the counseling staff began consulting them on the specific disabilities that the consultants' children have. The staff also discovered that the consultants, because of their extensive grassroots networks, provided expert advising on advocacy, access to technology, working with parents in crisis, locating resources, and other service interests. At various staff meetings, the consultants have provided incisive questions and comments from the parent point of view. Exposure to the Peer Consultants has given staff not only an expanded pool of information, but also a realistic view of parents as equal partners.

More discoveries await those groups willing to innovate with parents on staff. Based on our experience, the concept is well worth replicating.

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Parent Trainer Antonio Flores and Peer Consultant Marty Preciado discuss strategy for starting a local parent support group.

Kyle's Success Story

by Linda Horkheimer

Kent had a broken finger from football practice, Stacey broke her arm falling off her bicycle, and Tracy had a broken foot from flying through the air off the top bunkbed. "Just like Wonder Woman, Mom!" This all occurred within a six week period. I don't know why it came as such a shock when the doctor announced, (rather smugly, I thought) "Congratulations! You're approximately 12 weeks pregnant!" I don't remember his exact words, to be honest. I was slightly comatose at the time. I do remember thinking of some evil ways to wipe that smile off his face. But, then I decided no, I'd save them for my husband, as soon as he got home from work...

Well, time passed and each of the children's injuries healed. In March, I gave birth to a beautiful son, whom we named Kyle Patrick. He was by far the best baby I'd ever had. He was so good natured that he never cried, not even to eat in the middle of the night. It wasn't long before I began to suspect that something was wrong. He was progressing far too slowly. The doctors kept reassuring me that I must not compare Kyle to his brother and sisters and that each child is different and develops at his/her own pace. Kyle began seizing when he was nine months old (so much for their advice). His diagnosis included epilepsy, cerebral palsy, autistic behaviors, and developmental delays. I remember asking my husband whatever happened to the good old days of broken bones, chicken pox, and unexpected pregnancies?

The next 18 months are really just a blur of hospital rooms, doctors offices, more hospital visits, and more tears than I'd cried since I was a child. Kyle was about three years old when Marijo McBride of the Parent Case Management Project [see story at right] called and asked me if I'd be interested in participating in the program. I'm always eager to learn new things, especially in the disability related field, so I agreed. Little did I realize at the time the positive effect the program would have, not only in Kyle's life, but on our entire family!

I learned about family subsidy, the Waiver, and TEFRA. Believe me, that eased a lot of financial stress! But I was still feeling terribly frustrated with Kyle's education. He was attending a segregated preschool program. Common sense told me that a child with no speech, no social skills, and virtually no awareness of his surroundings did not need to be kept segregated, but rather needed to be around his typical peers so he could have appropriate behaviors to mimic, or at least respond to. Alas, I had little self-confidence and felt I had no right to argue with educated professionals. So, I didn't until after I'd humiliated myself for the umpteenth time by bursting into tears at yet another unsuccessful IEP meeting. Then, it finally registered. I was just as educated as everyone else in the room. I knew P.L. 94-142 from top to bottom. I knew the school district's responsibility to Kyle and I knew that what I was asking was not outrageous.

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Kyle (top) with his brother Kent has benefitted from Minnesota's Parent Case Management Project (see story at right).

Training Families to be Case Managers

The Parent Case Management Project of the University of Minnesota's Institute on Community Integration empowers parents and guardians of persons with developmental disabilities to be more effective and active participants in the case management of services being delivered to their sons or daughters or to themselves. The project is funded by a grant from the Minnesota Governor's Planning Council on Developmental Disabilities.

Participants take part in 40 hours of training, which develops the following competencies as they relate to their role as parent case managers:

- Ability to describe case management, rights and responsibilities, data privacy, human and civil rights, state-of-the-art service delivery and philosophy, quality indicators, transition, and the importance of integration.
- Ability to demonstrate their roles as parent case managers, effective use of resources, maintenance of appropriate records, and proper procedures for effective meetings.
- Ability to identify needs, services and resources; appropriate rules and regulations; and functional goals.

Participants complete a form indicating the types of support and monitoring that would best assist them in their continued participation in the project. Ongoing contact with project staff is one method used to provide that support and monitoring.

Through the Parent Case Management Project, flexible family support has been created, building on the unique capacities of each family and enhancing their empowerment.

Contributed by Marijo McBride, Coordinator, PCMP, Institute on Community Integration, 6 Pattee Hall, University of Minnesota, Minneapolis, MN 55455 • (612) 624-4848.

Technology as Family Support

by Rachel Wobschall and Erik Aasland

Over 20 percent of the people in the United States have some type of disability that affects not only their individual lives, but their families as well. When technology is used to assist individuals, it can also be a positive experience for families. Two such families -- the Norbecks and the Annens -- have found that technology is allowing them to enjoy watching their children's independence grow.

Lynn Norback has used the computer as an educational aid since she was seven. She has cerebral palsy and, as a result, has had minimal hand



Lynn Norbeck works independently on homework thanks to her computer.

control. With the help of "Electronic Answer Sheet", a computer software program, Lynn can complete a one page worksheet by herself in 20 minutes that once would have taken her an hour to do with her mother's help. Because Lynn does the work herself, she is able to enjoy her successes and experience her failures. She also benefits from the fact that computers, unlike people, are infinitely patient; if she makes a mistake, the computer with voice chip says with some programs,

"Oops, try again." Lynn's fine motor skills have improved, allowing her to now choose between writing with the computer or by hand. Her early computer use has helped her progress intellectually and has allowed increased independence. As a result, the role of Lynn's mother, Judy, in her daughter's homework has changed; Judy can now watch how Lynn learns and yet not be tempted to jump in and take care of everything for her.

Another person who has benefitted from technology is Becki Annen. For her the computer was an expression aid that far surpassed the picture book she had been using for communication. However, the computer was not portable enough to meet her needs so, at age nine, she went to Gillette Children's Hospital in St. Paul, Minnesota, in order to find technologies better suited to her. Specialists at Gillette modified a "touch-talker" and power wheelchair for her. With the new technology she was able to express herself more fully and show her outgoing nature. Soon after receiving the new devices, Becki was transferred from a special education class to a regular class, where she quickly made friends. The technology enabled her to realize her academic and personal potential. Becki's family is proud of her achievements and delighted with how fully she can now express herself.

Although technology helped both families in similar ways, the means they used to finance technology differed. Lynn's family bought the necessary software as they found computer programs that would interest

and assist Lynn. Becki's parents, on the other hand, were able to secure Medical Assistance for her devices.

How can other families learn about appropriate technology or gain access to it? Judy Norback has found assistance through PACER's Software



Becki Annen uses a "touch talker" to converse with classmates.

Lending Library and Computer Resource Center [see story on page 9 of IMPACT]. Becki's family recommends the staff at Gillette Children's Hospital.

A new source of information on available technology is the Assistive Technology Information Network. By calling the network one can find out what assistive devices are available, which companies manufacture specific devices, how much devices cost, and how to order a specific device. They may be reached at a nationwide toll-free number, 1-800-331-3027.

Rachel Wobschall is Executive Director for the S.T.A.R. Project and Erik Aasland is Public Policy Intern for S.T.A.R. The project is creating a statewide, consumer responsive, comprehensive approach to providing technology related devices and services for people with disabilities. Its address is S.T.A.R. Project, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55101.

Computers: Accessing a New World of Opportunity

No one could argue with the observation that computers have come a long way in the last ten years. Their power and usefulness have grown explosively, while prices have tumbled. But what about the computer user with special needs? How can people with disabilities, along with their parents and teachers, share in the benefits of the personal computer? There is no simple answer to that question, but part of the solution can be found at PACER Center, a Minnesota organization that works to improve the educational and vocational opportunities available to children and adults with disabilities.

The PACER Computer Resource Center is a free community resource dedicated to making computer technology accessible to people with disabilities. Since the center opened its doors in 1987, hundreds of parents, teachers, and computer users of all ages and disabilities have been assisted. As one parent commented, "I found a whole new world in something I used to dread having to learn about."

The center serves Minnesota parents and professionals in four ways:

- **Consultations.** Parents, professionals, and people with disabilities can arrange a time to come into the center to try out a variety of adaptive computer products and software. Staff members Dan Berks and Rosalie Backer can offer observations and assist novices to zero in on the best solution for their or their child's computer needs. -- *"Without your guidance we would not have known whether a computer was right for Michael. He just loves working with the computer, and it also helps the school district since it is part of their program."*

- **Information.** When a parent, professional, or person with a disability is having trouble locating information on adaptive devices or software, center staff can help them find answers. The center has extensive files on computer adaptations and software, as well as a computer link to other resource centers across the country. -- *"You are a wealth of information...You made me more aware of programs to assist in educating and motivating children to learn."*

- **Workshops.** The center conducts free workshops throughout Minnesota for parents, professionals, and others interested in computer adaptation. These workshops cover a range of topics, from general computer adaptation to hands-on workshops concentrating on a single adaptive device. -- *"I enjoyed hearing a parent talk about the experiences with her child...We were impressed with your center but mostly with your caring attitude."*

- **Software Library.** The newest service offered is a lending library of educational and recreational software for use by children and young adults. Parents and professionals who are members of the library can borrow programs and special devices for use at home or school. -- *"Without the lending library I maybe would have spent money on programs that Jeff wouldn't have enjoyed and therefore wouldn't have been able to help him excel in so many areas."*

Most services provided by the PACER Computer Resource Center are free. For further information call the center at (612) 827-2966 (Voice and TDD), or write to PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417.

Contributed by Jon Skaalen, Communications Manager, PACER.

Kyle, continued from page 7

I was no longer, 'just a mom'. I was Kyle's Parent Case Manager and I wanted more for him than the segregated special education class. And I said so. The school and I began to work together. It was no longer "we" and "they", it was "us". The team was no longer focused on Kyle's disabilities, but on his capabilities, and wonderful things began to happen!

Kyle is presently attending a typical first grade classroom in his neighborhood school. He is following directions, is very aware of what's happening around him, is eating one meal a day orally, is experiencing less difficulty making the transition from one activity to another, and hasn't bitten his arm in months. Most importantly, Kyle has made many friends! One little boy calls him on the telephone, even though Kyle has no speech (what are mere words among friends?).

Kyle hasn't been the only one to benefit from his presence in a regular class. His classmates have learned to accept human differences. They've certainly learned to be patient and tolerant! If Kyle tries to take someone's pencil, they'll say, "That's my pencil, here is yours." If he's making inappropriate noises they'll tell him to be quiet so they can hear. When the teacher is questioning the class, they will raise his hand and answer for him. They try to include him in games and activities, and they're so proud when he throws away his own art scraps and puts away his glue and scissors. They even wipe the drool from his chin. The children are all learning together and it's been exciting! As two of Kyle's friends pointed out, "We would never be mean to Kyle because we love him too much." And, "Kyle isn't different, he's the same as us on the inside!" How far we've all come since I received that one brief phone call!

Linda Horkheimer lives in Cottage Grove, Minnesota, with her husband Richard, her son Kyle, and three other children.

From Surviving to Thriving: One Family's Transformation

by Cindy Scattergood

Once people find out you are a parent of a child with a developmental disability, there seems to be a misconception that somehow you were chosen and that you wouldn't be given more than you can handle! Our daughter Jamie was diagnosed around age two with mental retardation and a seizure disorder. I think the hardest thing for me was admitting to myself that I couldn't handle her. The guilt I felt was overwhelming. Why was I having such a hard time being her mom, and why couldn't I cope?

I remember when I first mentioned looking into respite care to my husband, Bill, so we could get a break. He was stunned. How could we do this to our own child? But, we also had to realize that if we didn't take care of ourselves, we couldn't give Jamie everything she needed. If you asked Bill about respite today, he would tell you how much it has enriched Jamie's life and made us better parents. Jamie first started going to respite once a month for the weekend at age three. Sure in the beginning it was hard emotionally, and we went through several families that didn't want Jamie to come back because of her challenging behaviors and her need for constant supervision. But now, five years later, it is a much different story. Jamie has spent the last four and a half years with the same family. At different points she spent a month, three months, and finally one full year with them. And still today she continues to go every other weekend to their home. They have been a tremendous support to our family, and have provided her with positive role models and many rewarding experiences in their community. We could not have survived without them.

Placing Jamie for that year was one of the hardest decisions we have ever faced. But we truly felt our family could no longer continue the way we were. Life became day to day survival for all of us, and at that time we could not get any in-home support, so it really seemed our only option. During that year while Jamie was in respite, we began to see some very positive changes in her. I look back now and see that we were just too physically and emotionally exhausted with the daily challenges she brought to our life to make those changes happen ourselves. She attended a regular kindergarten with an aide for six months and attended a regular YMCA day camp for the first time. They both seemed to have a positive effect on her. Also during

that year, Bill and I decided we needed more than anything else to educate ourselves on Jamie's rights and on what services were available. I felt very fortunate to be a part of the Partners in Policymaking program [see page 15 of IMPACT], put on by the Governor's Planning Council on Developmental Disabilities. I learned to be assertive, and it

gave me drive to speak out on behalf of all families. I feel now that this had a great impact on our receiving services for Jamie and our family.

Jamie came home just before her year was up, with the services we felt she needed. I feel this was a major turning point in her life! We decided when she came home that she would go on to first grade with a full-time aide and that she needed to get out into the community with regular kids. So with the help of her waived services team, we decided that she would attend an after-school latchkey program three days a week. But we knew Jamie could not handle being placed in a regular setting without assistance. So they hired on an implementor through waiver to

attend with her. That first year they worked on interaction, play, and bathroom skills. We saw success. We could see Jamie learning more appropriate behavior. And for the first time out in the community we began running into kids that knew her and wanted to talk to her. Although Jamie's speech is delayed, we worked hard on her just saying "Hi" and we saw first hand that it was working. It really seemed by the end of the school year that she had blossomed!

We also decided when she came home that we really needed help with the girls' interaction. Jamie's younger sister, Jenny, seemed to be having a hard time dealing with some of Jamie's behaviors towards her. We really felt in many ways that Jenny was trying to mother Jamie, telling her exactly how, where, and what to play. We felt this was very unhealthy for Jenny, so we had an implementor from waiver come one night a week to work with the girls. They have dinner together, go to the park or library, play games, and role play situations. We have been doing this for the last year and a half and we all look forward to that night every week; Bill and I enjoy that time away together and the girls really feel it is their special time.

This year Jamie went on to second grade and continues to go to latchkey after school with her implementor.

Jamie, continued on page 18



Jamie proudly wears the badges she's earned in her Girl Scout troop.

Teen Sitters Offer Child Care Alternative

When you are looking for childcare, who do you call? A friend, family members, or county offices? In the 1990s there is a whole new option available to parents of children with special needs, called *Special Sitters*.

The Minneapolis and St. Paul Councils of Camp Fire, in conjunction with ARC of Anoka and Hennepin counties, offers training to teens ages 13 to 19 who desire to become sitters for children under age 13 with special needs. The 15 hour training program includes the following components:

- **Communicating With Parents:** Sitters learn how to listen to parents, to gather information about each child's care, to negotiate a wage for service, to build rapport with parents, and to express their own capacities, needs and feelings.
- **Responsive Play:** Sitters discover ways to play with children of varying ages and abilities in a manner that is responsive to the individual child and, at the same time, fun for the sitter.
- **Keeping Your Time Together Enjoyable:** Sitters learn to follow parent-directed behavior programs, to anticipate and respond to a spectrum of behavior.

- **Communicating with Children:** Sitters experience alternative communication systems and learn the importance of expressing and responding, both verbally and nonverbally, to children.

- **Individual Capacities and Needs:** Sitters discuss their own feelings about being a sitter and the feelings of the children and families they serve. A variety of adaptive technology is seen and discussed, as well.

- **Red Cross Training:** Sitters take eight hours of training.

While not qualified to care for every child with disabilities, the sitters are well trained and offer many families another option in child care. This program can provide a more natural alternative to parents by letting them choose babysitters right in their own neighborhoods. In the future, *Special Sitters* will give our communities more ways to promote integration, too!

Contributed by Anita Lavasseur, Minneapolis Council of Camp Fire, 4100 Vernon Avenue South, Minneapolis, MN 55416. For more information on Special Sitters call Barb Nyquist at Camp Fire in Minneapolis, (612) 925-0205.

Respitality: Giving Families a Break

In the early 1980s, a United Cerebral Palsy affiliate in Mobile, Alabama, developed a novel approach to helping families. They combined respite care with hospitality (hotel rooms, meals, entertainment) donated by the community and called it *Respitality*. Since then, respatiality programs have been replicated nationwide.

In Minnesota, UCP's *Give Me a Break* respatiality program began with the formation of an advisory committee made up of parents and professionals. Even though there was consensus that respatiality was a needed service, a survey was done to document the need and to assist in marketing. The survey results indicated that over half of the families questioned were receiving no respite services, relied on extended family for childcare, and typically had their away from home every two months or less. Ninety-five percent felt respatiality would be very helpful.

At this writing, *Give Me a Break* is in a pilot program phase through the fall of 1990. The committee chose to begin with a pilot to help determine eligibility criteria and work out any unforeseen problems. During the pilot, eligibility has been limited to state residents

who have a child age one through eighteen who has a disability and lives at home. Preference is given to families of children with motor disabilities. Four different time packages are offered, ranging from four evenings off to an entire weekend, combined with hotel rooms, meals and entertainment. Thus far the pilot project has revealed that the need/desire for respatiality is great even among families with regular care in place. Requests for respatiality come in months in advance. Another discovery is that the hospitality industry is inundated with requests for donations and is more likely to give care (if at all) rather than act as an ongoing bank.

The success of *Give Me a Break* is best reflected in the fact that parents love the program. These families are using it for special occasions, such as birthday or anniversary weekends. And though they may have to get in their request far in advance, as one parent commented, "The anticipation was just as wonderful as the weekend!"

Contributed by Maureen Harms, Board Member, United Cerebral Palsy of Minnesota, 1821 University Avenue, Suite 233S, St. Paul, MN 55104.

In-Home Support from a User's Point of View

by Dorothy and Edward Skarnulis

As public policy in developmental disabilities has increasingly begun to shift toward real homes, including greater control by people with disabilities and their families, we're discovering a different world than the one we knew. The time is coming when the people being served can be in the driver's seat, when they can increasingly tailor-make the world to fit their own unique needs, and not be subjected to the limited menu of traditional specialized provider agencies.

The time is coming when the people being served can be in the driver's seat...

So then why the ambivalence? You want control, to be empowered, but you don't want a loss of all supports. You're scared. Since most staff come to you with no experience and minimal or no training, you don't know how to take somebody off the streets, or somebody who's worked only in congregate settings, and train or direct them. You're not a trainer. You're not an administrator. You're not a supervisor. You're just a human being with a disability, or a parent, trying to create a positive relationship with these strangers who live and/or work in your home. You need them. You're dependent on them. You want the relationship to be friendly. But, you also know that there's a fine line between friendship and loss of control.

Homes are intimate environments, where people want to feel comfortable. Even a small amount of friction magnifies itself in a home because people can't avoid each other. It's the same kind of intimacy that all parents, children, siblings, and spouses experience.

Living together raises a number of important issues, such as "Why don't

you put the cap back on the toothpaste? For that matter, why do you squeeze it from the middle rather than the bottom?" "What? No Downy in the wash? My clothes feel like sandpaper!" "Please, please, please vacuum the kitchen carpet after every meal." "Don't give Michael chocolate milk with supper or he won't eat." "I've told you, you have to let Mary bear some of the weight or she'll let you do all the work." "Please, while we're gone, let the dog out first thing in the morning or he'll make a mess." And so on. Sometimes the "do's and don't's" lists that parents leave for new staff are like a volume of *War and Peace*.

Perhaps the best training in the world to prepare someone to live in others' homes is that of the British nanny or gentleman's gentleman. Both professions begin with the frame of mind that says, we are here to serve. They try to be unobtrusive. Their goal is to make their work appear to be effortless. They strive to maintain harmony and avoid conflict. They are careful to be non-judgmental, although they may of course have private opinions about those they serve. They recognize that for things to flow smoothly, one must anticipate needs. That in turn requires a high degree of organizational skill. Look closely at families that have adapted best to the presence of a member with a disability, and you'll usually see an enormous amount of time and energy devoted to individual or collective scheduling, coordination, and cooperation. We could learn from the British in our training of support staff.

Active Treatment, Habilitation, Training. Holy words in the lexicon of developmental disabilities, and especially when public funds (read "Medicaid") are used. Is this a family support service, with the emphasis on keeping the family intact as the primary means for preventing the need for

expensive, out of home placement? Or is the service provided primarily to elicit new skills for the person with the disabilities? Obviously, it can be both. But, if staff have been trained in an Intermediate Care Facility (for people with mental retardation) where a heavy skill development frame of reference is required, and the person with disabilities or the person's family is mainly concerned about responsiveness to daily living needs, the potential for conflict exists. Even constructive strategies, such as using the natural environment as part of the learning experience, has limits. There are an awful lot of hours in a day.

What, then, is being done to prepare employees to serve people with disabilities and/or their families in the natural home? While some of the pro-

A good start toward achieving consumer satisfaction would be a belief system and personnel preparation program that comes closer to the values reflected in the British nanny/valet roles...

grams that award titles such as QMRP, Human Services Technician, or Program Coordinator do provide a solid information base that qualifies the graduates to make a positive difference in the lives of the people they serve, many of them don't. What's important? Knowing how to communicate with the person who has difficulty communicating. This is a skill many family members have honed over the years. They can recognize fatigue, hunger, illness, boredom, when strangers can't. They can also interpret preferences, choices, likes and dislikes. All of the

Support, continued on page 17

ARC = Parent Power

Building on the old adage that knowledge is power, ARC - Minnesota offers a number of programs that give parents and others access to resources knowledge, and opportunities for skill building in the area of family support.

■ **Parent Power:** This program offers 25 workshops a year throughout the state covering topics such as laws and rights, available services and funding sources, and parent advocacy skills. New workshop topics are developed each year to keep pace with changing needs and desires of families. Participants receive "how-to" handbooks on topics such as integration of a child into regular education and obtaining occupational and physical therapy services in public schools.

■ **Peer Advocacy Training:** Through this project Minnesota parents are trained to be advocates for each other in the case management system. The goal of the project is to provide parents or

guardians of people with mental retardation or related conditions with the information, training, and support needed to successfully obtain and improve services.

■ **Early Intervention Program:** This program offers intensive training to empower Minnesota parents of young children with disabilities as they seek quality early intervention services for their child and advocate for change.

■ **Phone Information Service:** Parents and other family members in Minnesota may call a toll-free number and quickly access resources that offer practical options for coping with questions, stressors, and medical concerns.

Contributed by Karen Grykiewicz, Associate Director, ARC Minnesota. For further information on these and other ARC programs, contact ARC Minnesota at (612) 827-5641 or toll-free (Minnesota only) (800) 582-5256.

Information on Family Support

• **Family support services in the United States: An end of decade status report** [see IMPACT cover story]. Contains detailed description of national trends in family supports and state-by-state summary of family support programs. Cost: \$15 post paid. Available from Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge MA 02140.

• **IMPACT: Feature Issue on Consumer Controlled Housing.** Explores options in home ownership for persons with developmental disabilities and their families. First copy free; additional copies \$2. Available from Institute on Community Integration, University of Minnesota, 100 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455 • 612-624-4512.

• **Newsletter, strategies of practice and research** from the Beach Center on Families and Disability [see inside of right]. Available from Hattie Shiller, Beach Center on Families and Disability, c/o Bureau of Child Research, Haworth Hall, University of Kansas, Lawrence, KS 66045.

• **National Information Center for Children and Youth with Disabilities.** Offers resources to assist parents who are helping young people with disabilities become participating community members. P.O. Box 1402, Washington, D.C. 20013 • (703) 693-6361, (800) 999-5398.

• **The Family Support Bulletin.** Available from United Cerebral Palsy Association, Community Service Division, 1522 K Street NW, Suite 1112, Washington, D.C. 20005 • (800) USA-SUCP.

Project Seeks Answers From Families

by Ann and Rud Turnbull

What does it take to support families who have members with disabilities? At the Beach Center on Families and Disability at the University of Kansas we know there are many answers, but we think the best may come from families themselves. So, two of the Center's research projects are seeking answers by asking families, and another is using those answers to help states develop appropriate laws and policies of family support.

One research project asks: "What do families need to prevent out-of-home placement?" Answers are being sought through research with Minnesota family members who have children with emotional disorders, developmental disabilities, or who use technology-support services. This research is seeking to determine the state policies, programs, supports, and values regarding "reasonable efforts" that are most likely to help families maintain their children in the least restrictive, most home-like environments.

A second project seeks to identify the major characteristics of ideal family support programs through studying the literature on family support. Once the ideal programs are identified, researchers will interview families who receive services from those projects, asking about the project's impacts on their lives and their additional unmet needs.

A third project proposes to create a model state family support law by conducting a policy analysis of family support, conducting research into the laws of all states for typical and unusual approaches to family support, and developing a model law.

For further information about our research or if you're interested in participating, write to Ann and Rud Turnbull, Co-Directors, Beach Center on Families and Disability, c/o Bureau of Child Research, Haworth Hall, University of Kansas, Lawrence, KS 66045.

Families Educating Policymakers About Family Support

by Fran Smith

Families in 10 states are involved in a process that is empowering them to educate and influence policymakers about the needs of families of children with disabilities and about the reasons that public policy should support families to maintain their children at home. These activities are part of a project called, *Parents Influencing Policy Makers*,* sponsored by the Human Services Research Institute in Cambridge, Massachusetts, and United Cerebral Palsy Associations, Community Services Division, in Washington, D.C. The project is based on the principle that families know their own needs best and, therefore, should be the primary educators of policymakers.

Families in the project agree to attend a two day training session conducted by project staff to prepare them to participate in the legislative process. At the beginning of the training session, they spend time talking about what they need to know to communicate effectively with policymakers and the barriers to becoming involved in the legislative process. Some barriers that are frequently identified by families include their own lack of understanding of the legislative process, their lack of knowledge about family support, their feeling that they can't make a difference, their lack of confidence in their ability to express themselves effectively, and their sense that politicians don't care about children with disabilities. Once the negatives are listed, the positive work begins.

The training process is a mixture of presentation of new information, small group discussions, and communication with actual policymakers in a practice session. The following is a brief description of the training content:

- **Building a Vision:** In small groups, individuals imagine it is now the year 2005 and everything they ever wanted to accomplish in the area of family support has been achieved. They then translate that vision into present tense statements, which each group reports to the total group. As participants express their collective vision, they begin to want it in their hearts and believe that together they can make it happen.
- **Principles of Family Support:** After each group reports their vision statements, the total group refines the universe of ideas into a few principles that encompass the key themes, frequently including the premises that families know their own needs best, support services should be family centered and enable and empower families to make informed choices, services must be responsive to the needs of individual families, and that funding must be flexible.
- **Examples of Family Support in Other States:** The trainers present information about the array of family support services listed in the 1990 publication of the Human

Services Research Institute, "Family Support Services in the United States: An End of the Decade Report." (see page 13 of IMPACT for information on this publication).

- **Clarifying Values:** Individuals work with others who graduated from high school in the same decade to explore how their basic values were shaped by the events happening during that time. Discussion leads to understanding how policymakers who have not had significant life experience with people with disabilities may hold different values.
- **The Legislative Process:** The legislative handbook from each state is used to identify how an idea moves through the steps in the legislative process to become a law and to illustrate how families can influence the process.
- **Guidelines for Preparing for a Meeting with an Elected Official:** Guidelines that have proven successful, together with an agenda for a 10 minute meeting with an elected official, are presented. Participants work in small groups to identify the key points they will make, select the facts they will use, choose personal stories that will be remembered, and decide who will say what in a meeting with their elected official.
- **Practice Meeting:** Elected officials join the group for a 10 minute meeting in which they listen to individuals practice communicating with elected officials. At the end the legislators give constructive feedback to the groups.
- **Letter Writing and Telephone Trees:** Tips on writing an effective five paragraph letter, and on structuring and implementing a telephone tree, round-out the training.
- **Next Steps:** Each group concludes the training by developing a strategy to create, revise, and/or enhance state public policy.

The outcome of this training is that families are finding each other, supporting each other, and learning that they can make a difference. Their effectiveness is perhaps best illustrated by the experience of one mother who reports that when parents activated their telephone network in her state, the chair of Senate appropriations called her at home at 6:00 pm as she was preparing dinner for her noisy preschoolers and told her to "call off her honchos". Parent power is getting results.

Fran Smith is Director of Training for United Cerebral Palsy Associations, 1522 K Street, Washington, DC 20005.

**Note: This project is funded by a grant from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services.*

Minnesota's Partners in Policymaking

by David Hancox and Thomas J. Zirpoli

It began as a simple question. How can we help young parents of children with disabilities and adults with disabilities continue the advocacy movement begun by parents of earlier generations? The answer was a simple one as well: empowerment. As a result, the Minnesota Governor's Planning Council on Developmental Disabilities initiated a leadership program called **Partners in Policymaking**. The program is built on the belief that individuals with disabilities and their families must be provided with the information and skills necessary to be effective partners in the development of public policy affecting their lives.

Partners in Policymaking (Partners) began in May, 1987. It is an education and training program providing young parents of children with disabilities and consumers with disabilities with: a) state-of-the-art philosophies and practices through experiences and readings; b) opportunities to meet and interact with key state and national professionals in the field of developmental disabilities; c) opportunities to meet and interact with community, state, and national policymakers; and d) advocacy skills and opportunities to practice these skills through role-play activities, group interactions, and out-of-class assignments. The result is increased empowerment and the ability to more effectively influence public officials.

Partners participants are recruited through mailings, advertising, and interviews. Individuals submit an application for review by an independent team of public and private members of the community, including parents and persons with disabilities. During the first three years of Partners, 35 participants were selected per year. In the fourth year, 30 participants were selected. Each group represents a balance of metro and non-metro, male and female, persons with and without disabilities, and minority and non-minority members.

Training is provided in eight sessions delivered over a nine month period. Sessions are held on Fridays from noon until 9 p.m. and Saturdays from 8 a.m. until 3 p.m. The program provides overnight accommodations for those traveling from outside the Minneapolis/St. Paul metropolitan area. In addition, participants are reimbursed for meals and travel, along with respite, child, or attendant care as necessary. Training sessions include discussions on a) history, services, and values; b) county, state, and national issues; c) case management; d) quality integrated education; e) associations and organizations; f) physical disabilities and assistive technology; g) family issues; h) supported living and employment; and i) public meeting participation.

In addition to discussions, other activities are scheduled. For example, during a session on the state legislative process, a tour of the state capitol and visits with public policymakers were planned. Participants were informed about the process of a bill becoming law and how to effectively influence the process. Homework assignments include readings, personal contacts with public officials, organizing letter writing campaigns or petition drives, monitoring the movement of specific legislation, participating in community meetings, and testifying before local, state, and national committees.

Evaluation of the program includes two parts. First, participants evaluate each training session and the entire program. Second, follow-up evaluations at six-months after graduation are conducted to give participants a second opportunity to evaluate the program and to assess ongoing

advocacy activities since graduation. This follow-up data, when compared with baseline data on advocacy activities prior to program participation, allows program directors to evaluate real changes and outcomes in the lives of participants. Type and frequency of advocacy activities before

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Partners in Policymaking Participants: Advocacy Activities Before and After Partners

Activity	Before	After
Level of Contact		
National Officials	21%	70%
State Officials	39%	83%
Local Officials	39%	83%
Type of Contact		
Letters	31%	70%
Phone Calls	31%	92%
Office Visits	29%	57%
Other Types of Advocacy		
Testimony: Public Hearing	15%	17%
Service on Committee	35%	76%
Conference Presentation	27%	37%
Promotions to Parent Groups	23%	28%
TV/Radio Appearances	12%	8%
Published Newspaper Articles	23%	39%
Self-Evaluation of Advocacy Skills		
Excellent	04%	67%
Good to Very Good	23%	33%
Fair	50%	0%
Poor	23%	0%

Personal Futures Planning: A Focus on the Positive

by Kay Zwernik

Personal Futures Planning is a process that focuses on people's gifts, talents, and abilities rather than their deficiencies. It provides strategies for people with developmental disabilities to develop personal relationships, have positive roles in community life, increase their control of their own lives, and develop skills and abilities to achieve these goals. A Personal Futures Plan is a person's vision for what he or she would like to be and do, and represents an active plan for making change to realize the vision. It becomes an ongoing problem-solving process and is accomplished through a small group of people who agree to meet for mutual support, brainstorming, and strategizing. This circle of support, or person-centered team, makes commitments and takes action to ensure that changes will be accomplished for the person who is the focus of the effort.

The traditional or blueprint approach to planning for people with developmental disabilities, either in school programs or in adult services, is focused on deficit-finding. This deficit-finding is cumulative as it continues year after year. For each skill a person acquires and each objective a person meets, new deficits are identified and new goals developed. The traditional Individual Habilitation Plan (IHP) or the Individual Educational Plan (IEP) processes often end up justifying the continuance of deficit-finding and devaluation in the lives of people with disabilities.

Personal Futures Planning, however, is an interactive style of planning that emphasizes the process of planning rather than the product. A basic value in this approach is being "person centered." The focus is continually on the individual for whom the futures plan is being developed. Whereas traditional planning methods have tended to focus on services and to place a person into a slot in a program, futures planning does

not look at what services are available in the community or school, but rather considers the things that need to happen so that an individual can fully participate in society.

There are three steps involved in the Personal Futures Planning process. The first is creation of a personal profile representing comprehensive information

Personal Futures Planning is a process that focuses on people's gifts, talents, and abilities rather than their deficiencies.

about the individual. This profile is developed through a group interview with the focus person and those who know the person well. The information generated is displayed on the wall on a series of "maps" that describe the quality of the focus person's life. The second step is the development of a plan for the person based on the information gathered from the group. The final step is the commitment by a group of individuals, a circle of support, to form a network to help the person carry out the plan.

One of the maps in the personal profile is a relationship map. This map describes the people who are most important in a person's life and with whom the person has the most interaction. A typical map for a person receiving segregated services would be like that for a woman named Mary Loretta. She was living in a 15-bed group home and had only one or two community visits per year. She had no peer friends. Her only contacts were with family and paid human service workers. Her relationship map had large gaps. After developing a Personal Futures Plan for Mary Loretta, she moved to her own home with two housemates who provided

support for her to live in the community. Within a period of a few months her relationships changed dramatically and her map filled up. She visited many other homes frequently and made many friends, including six pets, which are very important to her. The change in the quantity and quality of her relationships demonstrates the amazing results that can happen when the process of Personal Futures Planning is used and implemented. Mary Loretta's family's vision for her as a result of her personal futures plan was full participation as a member of her community. They decided they wanted something different for her and her support circle assisted her in realizing it.

Personal Futures Planning can complement the Individual Habilitation Planning and Individual Educational Planning processes. A futures plan can help those involved with the focus person see the total person, recognize his or her desires and interests, and discover completely new ways of thinking about the future of the person. The habilitation plan can help support staff organize their work, and it can establish accountability among agencies for the implementation of certain strategies. Together, the futures plan and the educational or habilitation plan provide a more comprehensive and feasible approach to achieving the desired goals of the person.

It is not at all uncommon for family members to say at the end of the profile and planning meetings, "I can't believe it. This was such a positive experience. Everything was focused on his/her capacities and not on all the things he/she can't do. It was just wonderful, and I feel so optimistic about the future."

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formal education in the world doesn't provide that ability.

Some people are good "sensors". They're able to read subtle, non-verbal indicators of the feelings of those around them. The two people who have worked in our home are wonderful examples of people who can read other people and situations and respond accordingly. On the other hand, not everyone has this ability and they need more concrete direction. Sometimes a face to face discussion of expectations is required, perhaps facilitated by the case manager or the agency supervisor. It's because of the unique contributions different people can make to the lives of folks with disabilities that program planning is a shared responsibility. There needs to be a written agreement attached to the individual plan that says who's going to do what. In the world of family support the expectations of various contributors need to be addressed: What do you expect of me? Of us? Of our agency?

Fear of lawsuits, and sanctions imposed by governmental regulatory agencies have spawned a preoccupation with paper accountability and documentation. The result is careful cataloging of numbers having to do with staff and consumer activities, using disparate measures of perceived effectiveness and oversight, ranging from monthly fire drills, and medication administration, to staff car insurance policy numbers, seizure frequency, training program data, and a variety of "behavioral frequencies." While these concerns may be important, nothing looks sillier than one human being following another human being around a house, clipboard in hand, pretending to be inconspicuous while making tick marks on a chart. "Special" environments tend to encourage a focus on the differentness of the occupants while ordinary environments reinforce the similarities among those who live in them.

There is no neat resolution to some of the issues raised here. They're presented as just a few of the examples of new challenges in humanizing service delivery. Get together any group of people with disabilities, or families that use in-home support services, and they can go on indefinitely with other stories about their experiences. Many of the changes that need to occur don't lend themselves to the usual "fixes," like rules or regulations. Imagine regulations saying "All Colgate tubes will be squeezed bottom-up" or, "Only mild picante sauce will be used in Scandinavian families in Minnesota." However, a good start toward achieving consumer satisfaction would be a belief system and personnel preparation program that comes closer to the values reflected in the British nanny/valet roles alluded to above, values imbedded in the belief that the true employer is the person being served.

Dorothy Skarnulis is Executive Director of ARC - St. Paul, and parent of Michael Daley, a 20-year-old who lives with her and Ed. Ed Skarnulis is a researcher with the Minnesota Department of Human Services.

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and after program participation are summarized in the table in this article.

In addition to the quantitative data, qualitative statements about the program and its impact on families and individuals have also been collected, statements such as:

- "It's a relief to have the information and tools to see our daughter in a new light"
- "Partners in Policymaking has made me a more confident person and more aware of what can work."
- "I never noticed the barriers which hold him (my son) and I back from everyday life as we know it."

Partners in Policymaking has been and continues to be a great success. Graduates are interacting with local, state, and national policymakers regarding issues important to themselves and their families. Many graduates are now serving on committees and councils where public policy regarding persons with disabilities is developed. These and other graduates have reported a new or stronger feeling of empowerment as they learn to access the system and make a difference.

David Hancox is Director of the World Institute on Disability in Minneapolis. Thomas J. Zirpoli is Assistant Professor and Program Director in the Department of Special Education, College of St. Thomas, St. Paul, Minnesota. For additional information on Partners in Policymaking, call David Hancox at (612) 379-3969.

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P.L. 99-457 is a comprehensive law requiring the development of comprehensive statewide systems. Here we are only focusing on the IFSP sections of the law. There are many other sections that also require intensive planning by local, regional, and state level personnel working with families to meet their needs. We believe that if we can figure out the complexities of coordinating the services of the various agencies through the work we are doing around the IFSP, then someday in the future the IFSP can become a planning document for children of all ages, not just for children between birth and age three.

Excerpted from remarks of Norena A. Hale, Manager, Unique Learner Needs Section, Minnesota Department of Education, delivered at the IFSP teleconference sponsored by Minnesota's Interagency Planning Project for Young Children with Handicaps on January 10, 1990. Contributed by Jan Rubenstein, Coordinator of the Interagency Planning Project.

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development of an individualized package of services that meets the needs of the recipient. Within the program's cost limitations, the package is designed for the best possible "fit" for the child, as opposed to institutionally-based services, where services are less likely to be individualized.

For a child living in the family home, the service plan can encompass any of these services: case management; homemaker; noninstitutional respite care; day training and habilitation; in-home family support (includes training of the child and/or family members in such areas as addressing behavioral needs, therapeutic activities, personal development, medically related services, and assistance to the family in dealing with supervision, monitoring and stress management); and adaptive aids (such as wheelchair ramps, architectural modifications to the home, modifications to the vehicle, adaptive switches and furniture, protective coverings over radiators, windows, fireplaces and appliances, bath lifts, etc.). Waivered services can also be provided to eligible children in foster homes.

To qualify for the program, a child must have mental retardation or a related condition, and be eligible for the Medical Assistance program. Children under age 18 may become eligible despite parental income that would otherwise make them ineligible for Medical Assistance. Furthermore, the child must have been determined by a screening team to require placement in an ICF/MR within one year (or already reside in an ICF/MR), and have been determined by the screening team to need daily intervention.

The waiver program is administered locally by Minnesota's county human services agencies. Providers of waived services must be licensed by the Department of Human Services. The county agency case manager assigned to the family will determine the child's eligibility for services, conduct an assessment, convene a screening team meeting if the child is

determined to be at risk of ICF/MR placement, develop an Individual Service Plan (ISP), develop local service resources necessary to carry out the ISP, contract with service providers, and provide ongoing case management as required by state law. By law, the waiver program must be made available by all 87 counties. While there are currently waiting lists for waived services in most areas of the state, all counties are obligated to screen each person who requests waived services.

■ The Children's Home Care Option (CHCO)

Children who become eligible for the Medical Assistance Program through the Children's Home Care Option (CHCO) are entitled to the same benefits as all other persons who receive Medical Assistance. A Medical Assistance card is issued to the parent, who may use the card to purchase medically necessary items and services for the child from certified Medicaid vendors. Eligible children must be 18 years of age or younger, and must be certified as having disabilities by the Social Security Administration or the State Medical Review Team. Furthermore, the child must need home care that is comparable to care given by a hospital, nursing home, or ICF/MR, and if the child was in a hospital, nursing home, or ICF/MR, the child would be eligible for Medical Assistance. Home care for the child must be "cost-effective", that is, the cost to Medical Assistance for the home care must not exceed what the child's care would cost in the hospital, nursing home, or ICF/MR. Only the child's income and assets are counted in determining eligibility; the income and assets of the parent are not counted.

Some of the more common items and services families of children with developmental disabilities purchase through Medical Assistance include: physician office calls; diagnostic services; inpatient hospital; optometrist; physical, speech and occupational therapy; private duty nursing; home

health services; personal care attendants (PCAs); eyeglasses; medications; medical transportation; and incontinence supplies (including diapers).

There are approximately 1,000 Minnesota children now receiving Medical Assistance benefits through the Children's Home Care Option. Of that number, it is estimated that at least 75% have a developmental disability.

Parents wishing to apply for the Family Subsidy Program, the Home and Community-Based Waivered Services program, or the Children's Home Care Option, should contact their county social services agency and request a case manager (if they don't already have one). By law, the county agency must provide case management to all persons with developmental disabilities who request publicly funded services. The case manager should explain these and all other available programs and services to the parents, and assist them in selecting and coordinating the most appropriate ones to meet their child's individual needs.

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I remember a few months ago we attended a roller skating party with latchkey after school and I was surprised how many kids wanted to talk to her and how a number of them made it a point to come and tell me how they helped Jamie when she needed it. The funny thing is that Jamie really can't skate, but she insists on going because she says "Everybody be there"! That day I knew we were doing the right thing.

We know it is still a long road ahead. But the support we have received has made a tremendous difference in Jamie's life. For once we feel our family is thriving instead of surviving. We could have never imagined all this a couple of years ago!

The Scattergood family lives in Richfield, Minnesota.

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at least 129,777 families during the last state fiscal year. There is wide diversity in the extent to which family supports are firmly established in each state. Presently, only three states (Michigan, Wisconsin, and Minnesota) have relatively comprehensive family supports established by state legislation. Three other states (New Hampshire, Louisiana, and Illinois) have new legislation which, when fully implemented, will bring them close to a comprehensive array of supports. An additional 14 states have some supports that are mandated by state family support legislation. Eighteen states have family supports that are governed by departmental policy and are budgeted for in legislative appropriations; the informants in these states spoke of these supports as being a permanent part of the department budget. In seven states, family supports are small scale pilots funded by the state department or the developmental disabilities council.

The supports that are provided under the umbrella of family support fall into four general categories:

- The oldest and most generally available family support is respite services. Forty-six states provide for some degree of public support for respite for families of children with a developmental disability. In four states (Alabama, Delaware, New Mexico, and Vermont), the only state supported family support is respite.
- Thirty-six states fund other services in addition to respite as part of their array of family supports. In 13 states the support to families is limited to a group of designated services.
- Twenty-five states offer some form of financial assistance to families. Currently, in eight states the only state funded family support is some form of financial assistance.
- Finally, 17 states use combinations of financial assistance and services to provide support for families.

While there is extensive family support activity, the truly limited nature of most efforts becomes readily apparent when the number of families actually receiving support is examined. The range of families covered in each state ranges from nine in Wyoming to approximately 25,000 in California. In 15 states the major components of the family support program serve less than 100 families. Further, in some states with a large number of families on the eligibility rolls, it was reported that many families only receive case management services.

The average state allocation for family supports is \$3,826,623 (Range: \$37,880 in Wyoming to \$30,511,839 in California) for a national total of \$172,198,035. This figure is about 1.5% of the total national expenditure for services to people with mental retardation and developmental disabilities.

At this admittedly early stage in their development, supports for families of people with disabilities are at a crucial juncture. Almost every state has concluded that family support is something that it should do, but what remains undecided in most states is the direction these efforts will take. In general, the efforts we found were small scale and very new. Nationally, and in most individual states, the actual fiscal commitment to family support is a minute portion of the total budget for developmental disabilities services. Facility based programs continue to absorb the bulk of the resources. To this point most family support has been "sold" to policymakers based almost exclusively on a rationale of cost effectiveness. This is a crisis intervention perspective that sees the public sector providing just enough assistance to maintain the family and avoid the demand for expensive out of the home placement. Only in the last year or two have a few states begun to confront the basic message of family support: It is about the ultimate reconfiguration of developmental disabilities services away from facility-based models to a true community system.

Our reading of the direction in

family supports leads us to conclude that within the next decade each state will need to confront this fundamental decision about its policy direction. In its most concise form, the question confronting policy makers is, "Will we continue business as usual, placing our primary emphasis on funding programs and facilities and providing minimal support to families and adults with disabilities who live outside facilities? Or, will we shift to a truly individually driven system in which we fund the unique constellation of services and supports each person needs?"

In conclusion, a final point needs to be made regarding this or any efforts to describe state family support practices. There are likely to be significant differences between the ideal of family support as it emerges from interviews with policymakers and providers, or from review of state legislation, regulations, or other documents, and the reality of families' experiences. As an example, we can consider respite nominally the most readily available family support. Based on the figures presented in this report it would seem that most families that have a child with a developmental disability should be able to obtain some level of publicly supported respite. Yet in an earlier national survey of parent's experience with respite we found that although respite appears to be widely available, in many cases this service is not truly accessible to families. This suggests that future assessments of state family support efforts should supplement surveys of administrators and policy makers with evaluations by consumers. This approach will reveal the degree to which the ideals of parent-controlled, family-centered, community-focused supports are truly being realized.

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* See page 13 of IMPACT for information on obtaining the end-of-the-decade status report.

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- ... and more.

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